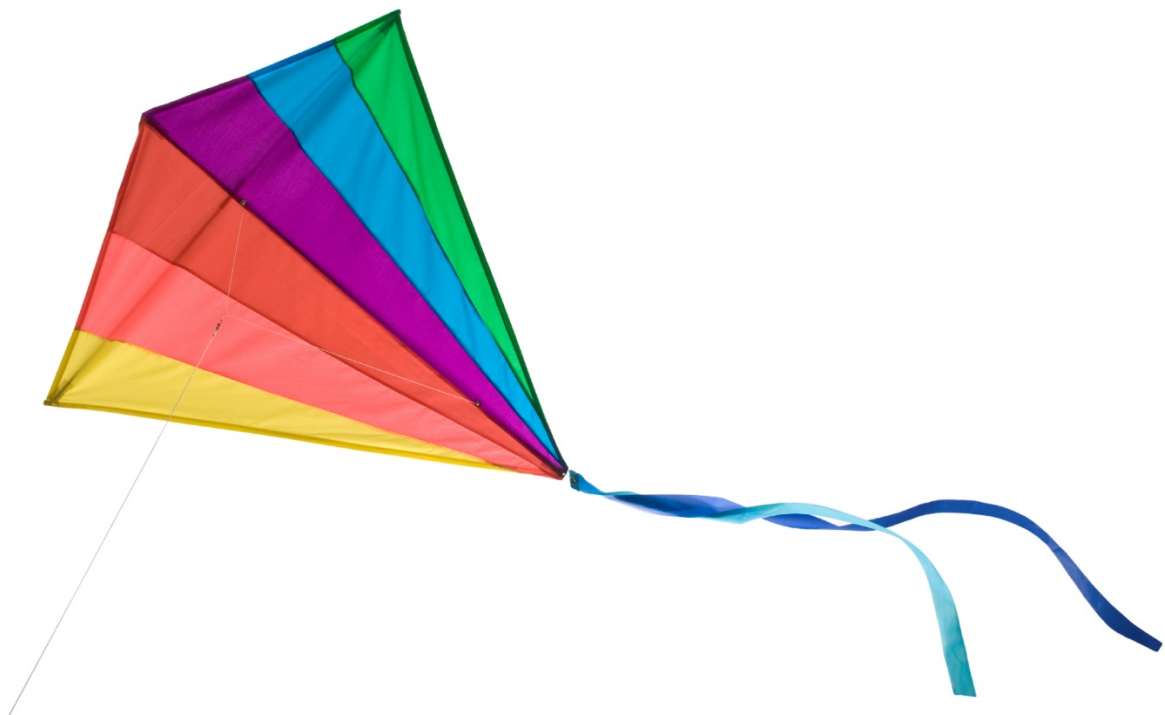


THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



Public Health
England

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**National Survey of Patient Activity Data
for Specialist Palliative Care Services
MDS Outpatients Report for the year
2013-2014**

About the National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions and promotes palliative care in health and social care settings across all sectors to government, national and local policy makers. For further information or to subscribe to NCPC to receive publications free of charge and reduced rates at conferences visit www.ncpc.org.uk

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About The National End of Life Care Intelligence Network

The National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England.

This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. NEoLCIN plays a vital role in supporting the comprehensive implementation of the strategy. On 1st April 2013 NEoLCIN became part of Public Health England, an executive agency of the Department of Health.



Public Health
England

The NEoLCIN website is www.endoflifecare-intelligence.org.uk
Public Health England's website is www.gov.uk/phe

About Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 220 member organisations that provide hospice care across the UK, so that they can deliver the highest quality care to people with terminal or life-limiting conditions and support their families.

Hospice UK supports the breadth, dynamism and flexibility of modern hospice care, by: influencing Government and decision makers; improving quality of care through the sharing of good practice; and providing resources, training, education and grant programmes.

We work collaboratively with our members to support their vital work and to create a stronger voice for hospice care in the UK. We also support the development of hospice and palliative care worldwide. Hospice UK's website is www.hospiceuk.org


hospice^{UK}

Outpatients MDS report 2013/14

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Key findings

- On average, each reporting service is seeing an increasing number of patients, up to 322 people seen per service in 2013/14 from 250 in 2008/09
- Outpatient settings consistently see a higher proportion of younger women with breast cancer than other MDS settings, making their patient profile quite different

Definition

An Outpatient clinic is an administrative arrangement which allows people to see a doctor or other health care professional for consultation, investigation and minor treatment. Clinics do not necessarily have to be held at regular intervals or in the same location. A clinic usually lasts for one morning or afternoon.

Attendance at an Outpatient clinic is usually by appointment, but people may sometimes arrive and be seen without prior notice. Some clinics, such as 'walk-in' clinics, are designated wholly or partly for people without prior appointments. It is good practice for a patient arriving without an appointment to be allocated a time by the receptionist.

Some specialist palliative care services may struggle to differentiate between their Outpatient care and their Day Care; consequently it is possible that two different services which are similar in structure may be reported under different MDS categories.

Note on figures: where possible, the number of organisations providing each data item in each year is given in parentheses on each graph. Different organisations return MDS data from year to year, and so any historical trends presented here are subject to the caveat that the profile of services responding may be different from year to year.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

All tables referenced are available in the accompanying annex document.

To help interpret graphs that show quartiles, it may be useful to think of it as: 25% of services are below the blue line, 25% of services are above the red line, and 50% of services sit between the blue and red lines.

Response rate

149 of 264 Outpatient services returned MDS data in 2013/14 representing a 56.4% response rate, up from 50% in the previous MDS reporting year. The increase in response rate is largely due to auditing of the service directory, rather than an increase in organisations sending in data.

Table 6a: response rates by type of organisation and type of management, 2008-2014

	Hospice			Hospital			Community	NHS Trust	Total services responding
	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by NHS	
2008/09	12	77	23	50	2		2		166
2009/10	14	83	14	43			1		155
2010/11	15	88	13	35		5			156
2011/12	16	93		36	3		1	2	151
2012/13	12	96		40	2			1	151
2013/14	13	91		43	1			1	149

Number of patients

Although this year saw the lowest number of Outpatient returns since 2008/09, the total number of people seen by Outpatient services increased by almost 5,000 from the previous year, up to 47,984. The size of services ranges from those who see between 1 and 10 patients in a year, and those who see over 1,700 people.

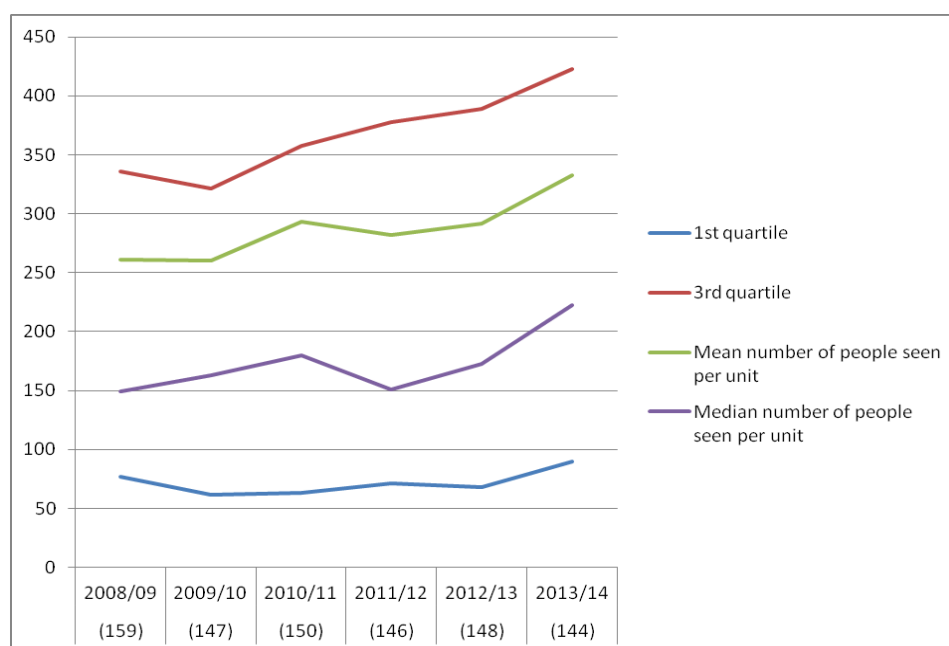


Figure 6.1: changes in the range of size of Outpatient clinics over time (Table 83)

Age of patients

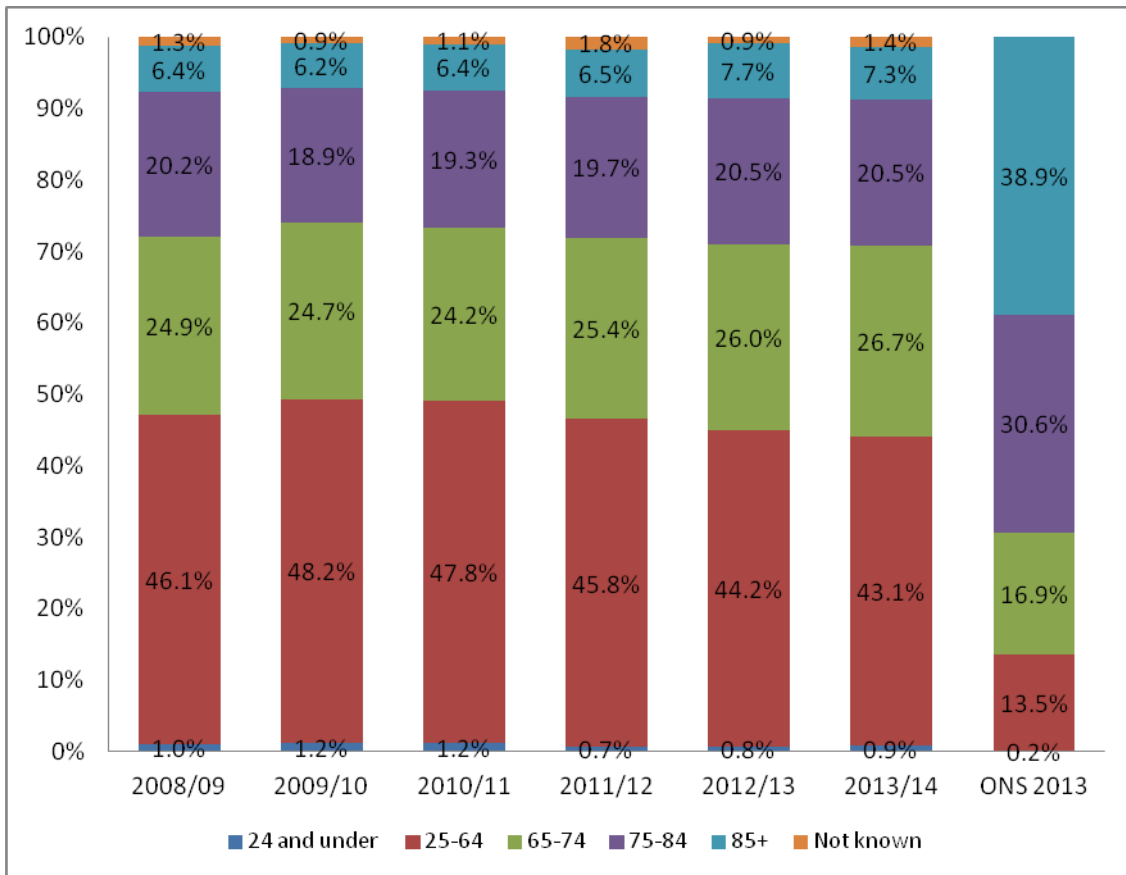


Figure 6.2: proportion of different age groups accessing Outpatient clinics, 2008-2014 (Table 84)

Outpatient attendees skew younger than other specialist palliative care settings. This is likely to be aligned with the high proportion of women accessing Outpatient care, and the high proportion of people diagnosed with breast cancer recorded in the diagnosis data.

Sex

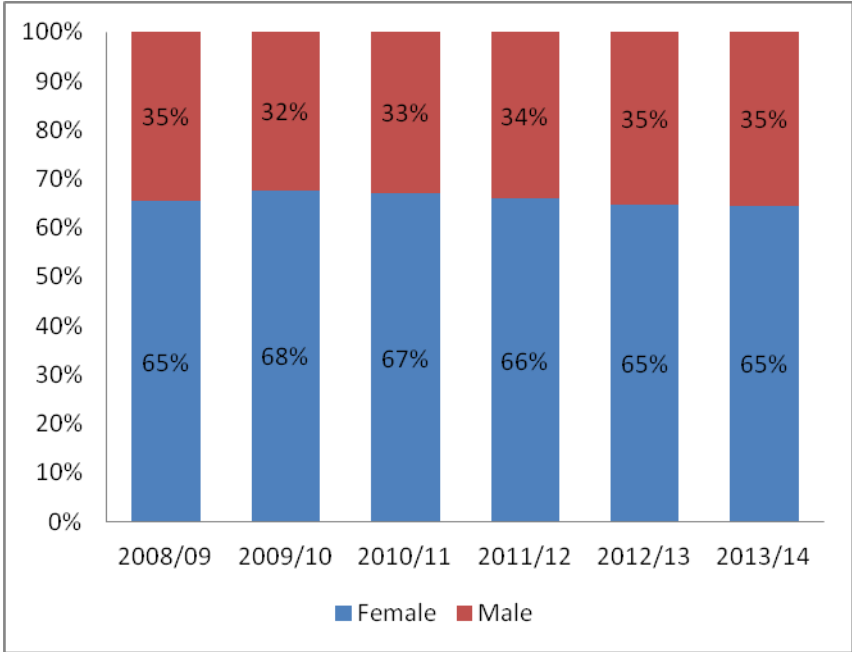


Figure 6.3: proportion of men and women accessing Outpatient clinics, 2008-2014 (Table 85)

Typically, more women than men access Outpatient services. This is again likely to be due to the increased number of younger women accessing breast cancer clinics.

Diagnoses

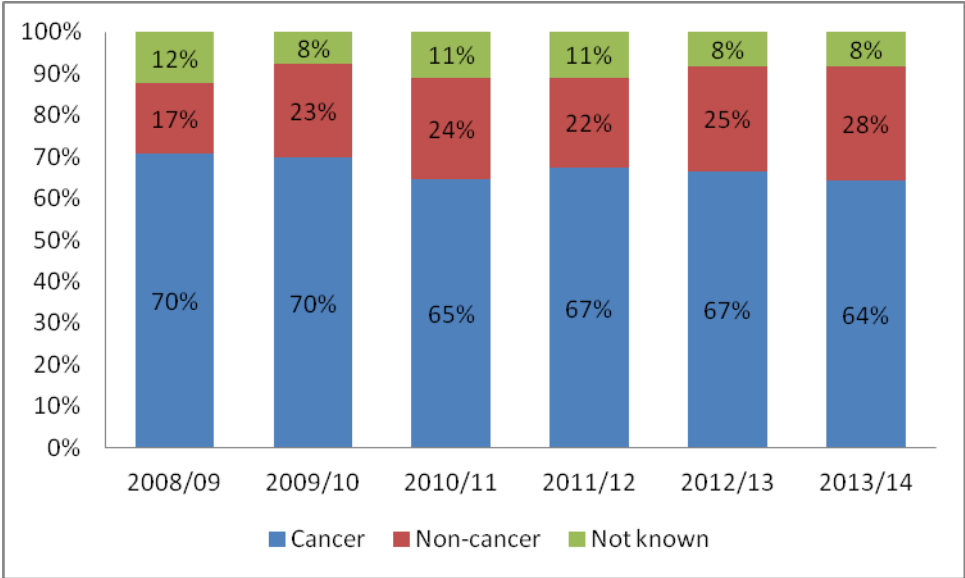


Figure 6.4: proportion of people with different categories of primary diagnosis accessing Outpatient clinics, 2008-2014 (Table 86)

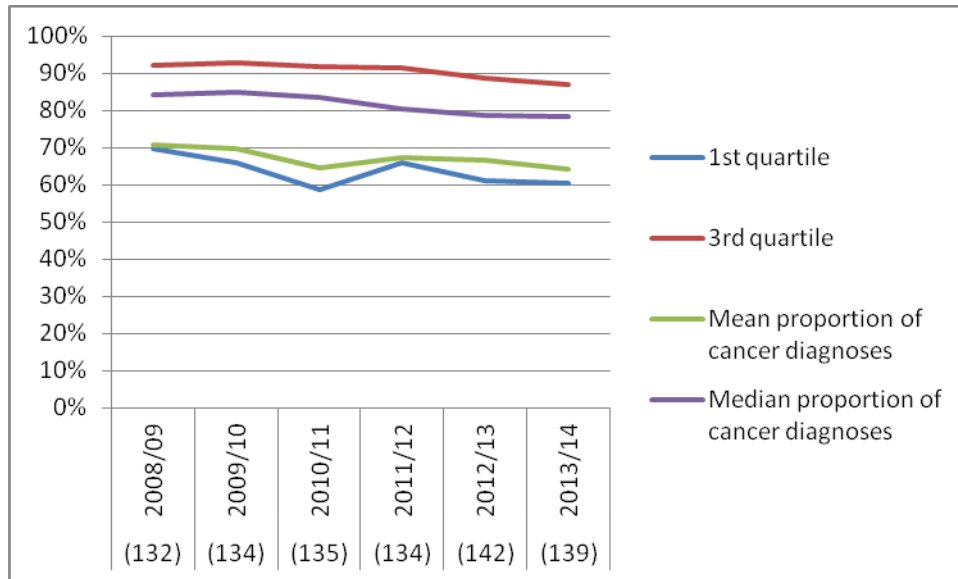


Figure 6.5: range in proportion of people with cancer diagnoses accessing Outpatient clinics, 2008-2014 (Table 87)

The average proportion of patients with a cancer diagnosis has dropped over time, from 71% in 2008/09 to 64% in 2013/14.

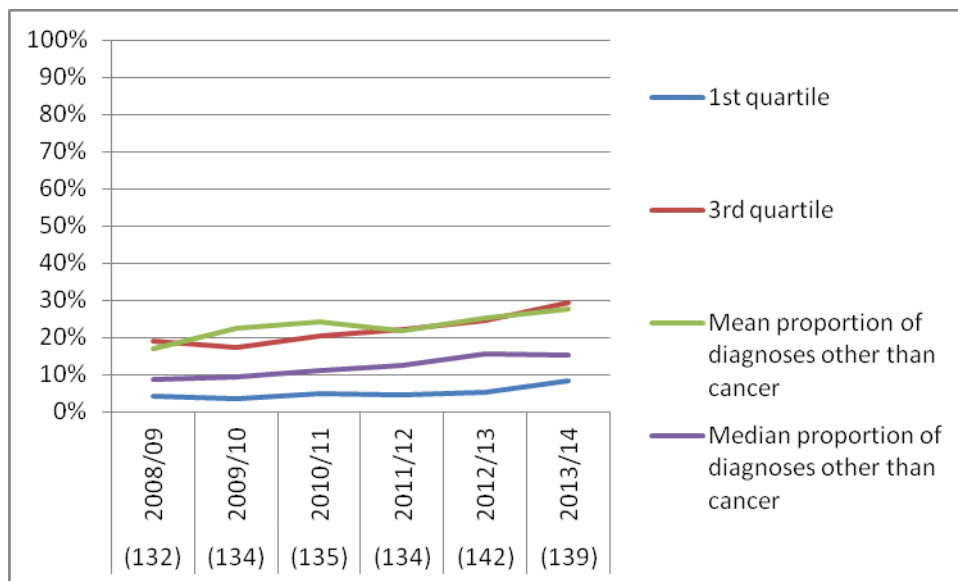


Figure 6.6: range in proportion of people with diagnoses other than cancer accessing Outpatient clinics, 2008-2014 (Table 88)

The proportion of patients with a diagnosis other than cancer has increased over this time period, although the average is being driven up by a few services who record a large proportion of people with diagnoses other than cancer; these may however be lymphoedema clinics recording that as a diagnosis rather than the underlying terminal condition, which could be masking a higher proportion of people with cancer diagnoses.

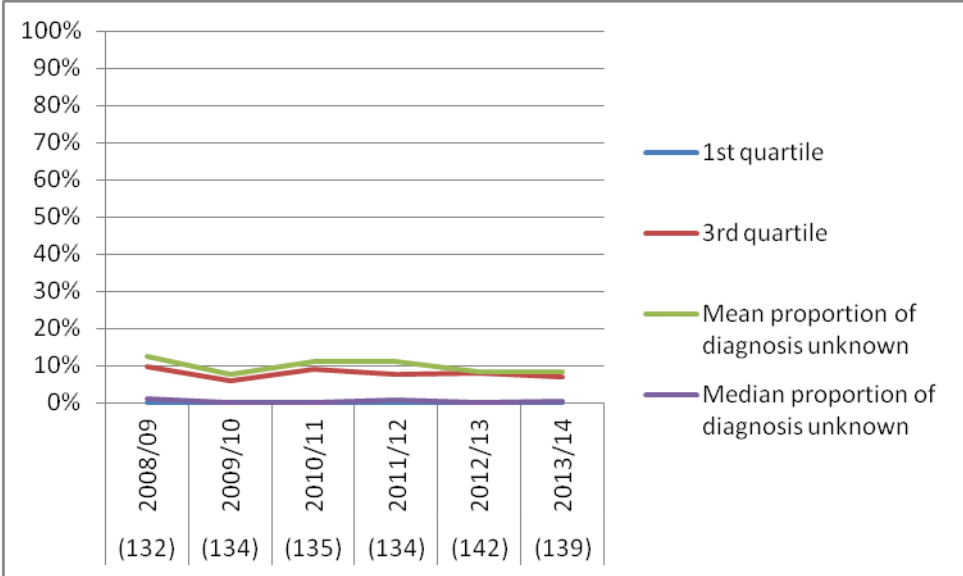


Figure 6.7: range in proportion of people with diagnoses unknown accessing Outpatient clinics, 2008-2014 (Table 89)

The given averages mask a wide range amongst services in the proportion of patients they see which each category of diagnosis. Each year, at least 6 services report that 100% of patients have cancer, while similarly each year at least 5 services report that 100% of patients have a diagnosis other than cancer. In each year there have also been at least 9 services reporting that the diagnosis of 100% of their patients was not known or not recorded.

Diagnosis breakdown: cancer

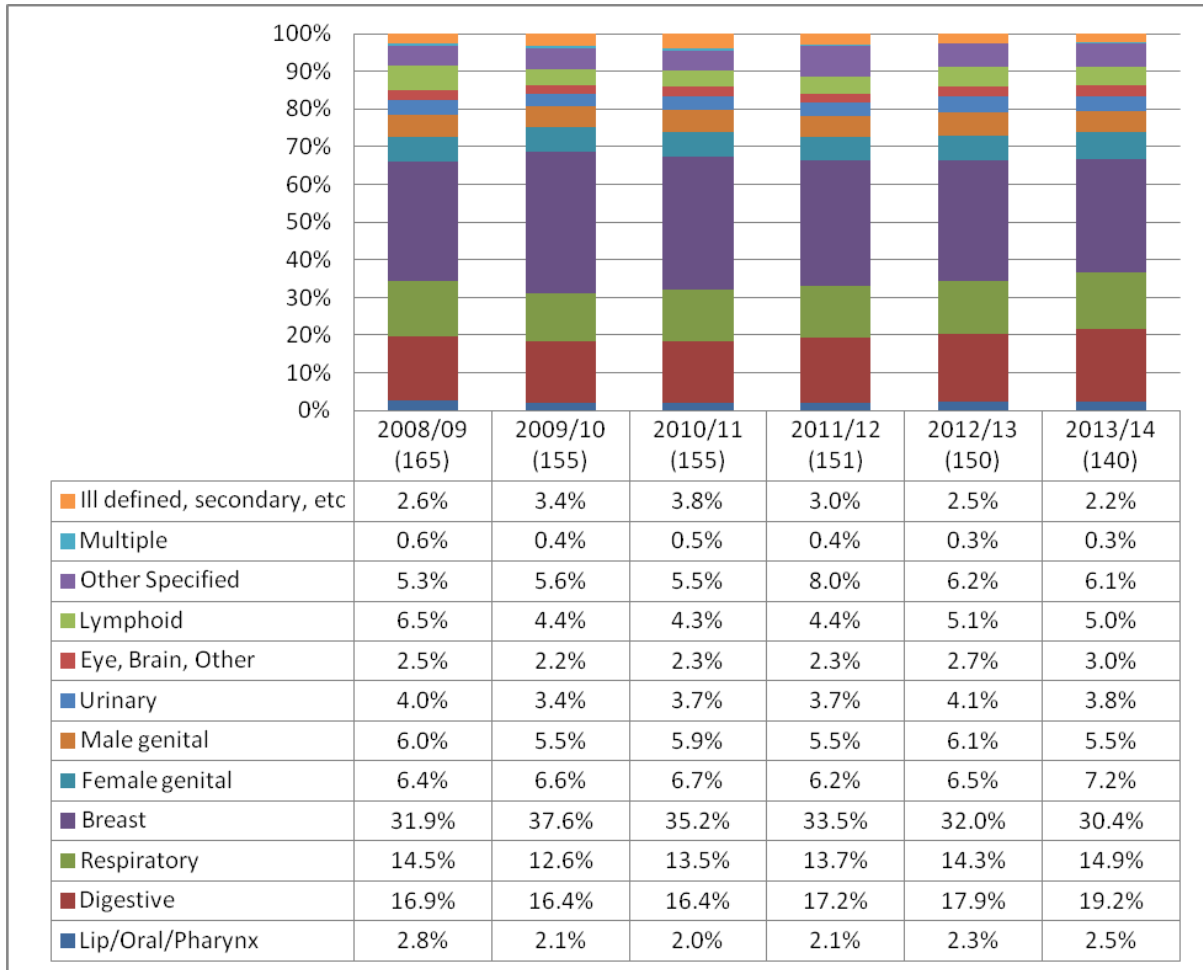


Figure 6.8: proportion of people with different cancer diagnoses accessing Outpatient clinics, 2008-2014 (Table 90)

Outpatients sees a higher proportion of people diagnosed with breast cancer than any other MDS setting. Otherwise, the proportions of each type of cancer treated in this setting remain relatively stable from year to year.

Diagnosis breakdown: diagnoses other than cancer

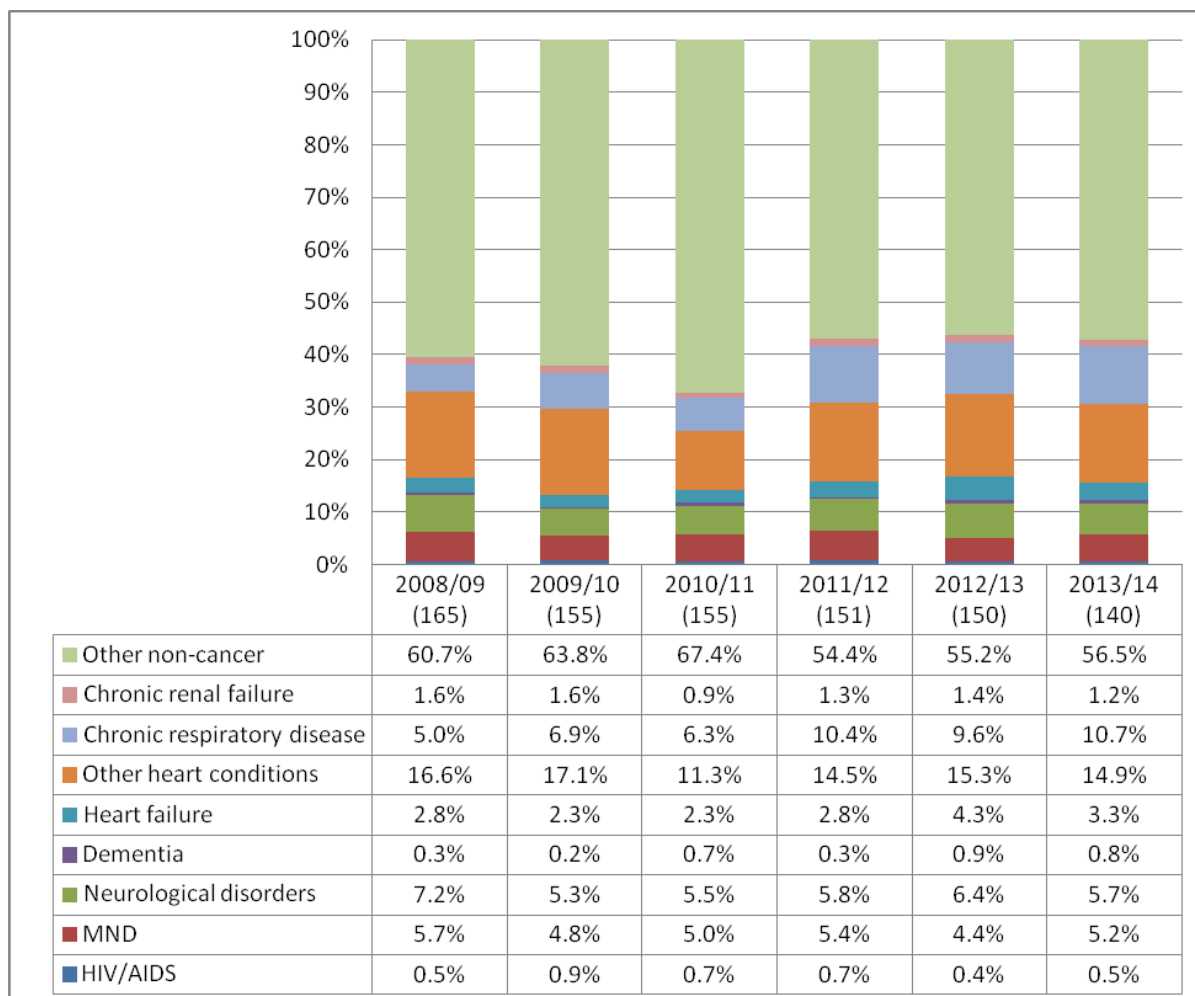


Figure 6.9: proportion of people with diagnoses other than cancer accessing Outpatient clinics, 2008-2014 (Table 91)

Outpatients has the highest proportion of 'Other non-cancer' of all MDS settings, which is likely to be due to the fact that many Outpatient returns come from lymphoedema clinics, and so lymphoedema is being recorded as the diagnosis. Further investigation is required to ascertain whether this is the case. As in other settings, there has been an increase in access for all conditions other than cancer recorded in the MDS.

Case study: Supporting Outpatients with chronic lung disease

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Lewis Manning Hospice

Since 2000 Lewis-Manning Hospice has run a breathlessness clinic, using non-pharmacological interventions (NPI) to help patients better manage their breathing. Initially the clinic saw patients with primary lung cancer, but over time has developed to support patients with cancer and chronic lung disease (CLD). Patients are seen on a one-to-one basis, rather than in a group setting. The CLDs affecting patients attending the clinic are mostly chronic obstructive pulmonary disease (COPD) at severe and very severe stages, pulmonary fibrosis and other interstitial lung diseases.

There is a strong body of evidence that supports the value of pulmonary rehabilitation for people with CLD. However, there is less evidence regarding individual NPI for patients with chronic lung disease. Patients referred to us are often unable to cope with pulmonary rehabilitation, due to physical and/or emotional frailty.

People with COPD have higher than average rates of anxiety, which can make pulmonary rehabilitation difficult for them. We work with these patients to help them explore the causes of their anxiety and then help them break the vicious circle. When this is successful, some patients are discharged from our clinic with a goal of going on to participate in pulmonary rehabilitation.

People with pulmonary fibrosis are often too physically frail to cope with pulmonary rehabilitation but can manage the “slower” pace of NPI. People with CLD frequently experience breathlessness, fatigue, anxiety and depression, these symptoms are often criteria for palliative care support.

NICE guidance for both COPD and pulmonary fibrosis recommend that palliative and best supportive care should be offered. However, attending our clinic is often the only link with palliative care for some patients with CLD. Whilst attending our clinic, patients can explore with us preferences for their future care. These can include preferred place of final care, decisions on resuscitation, intravenous antibiotics and invasive or non-invasive mechanical ventilation.

Pulmonary fibrosis has a prognosis of 2-5 years, which is similar to many cancers. In our clinic we consider the level of support a patient requires, rather than their diagnosis. An interesting observation is that some patients with CLD have been referred because their symptoms have deteriorated. Subsequent clinical investigations have revealed that they have developed a cancer in addition to their existing disease.

Ethnicity

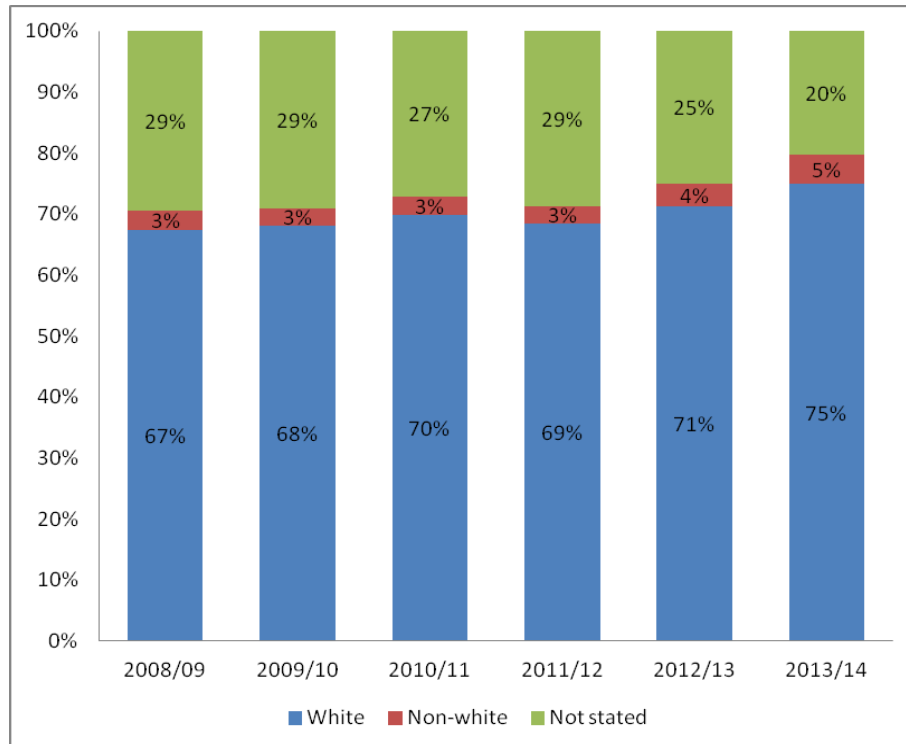


Figure 6.10: proportions of people accessing Outpatient clinics reported as white, BAME and not recorded, 2008-2014 (Table 93)

There has been a slight increase in the recording of ethnicity data, reducing the percentage of people where this information is unrecorded while the number of BAME people recorded as accessing Outpatient specialist palliative care has almost doubled over the past six years. As ethnicity is not a measure captured on death certificates, it is difficult to compare provision with prospective need, although we will look further into how this may be done using census data on the BAME population aged over 65 as a proxy measure for need.

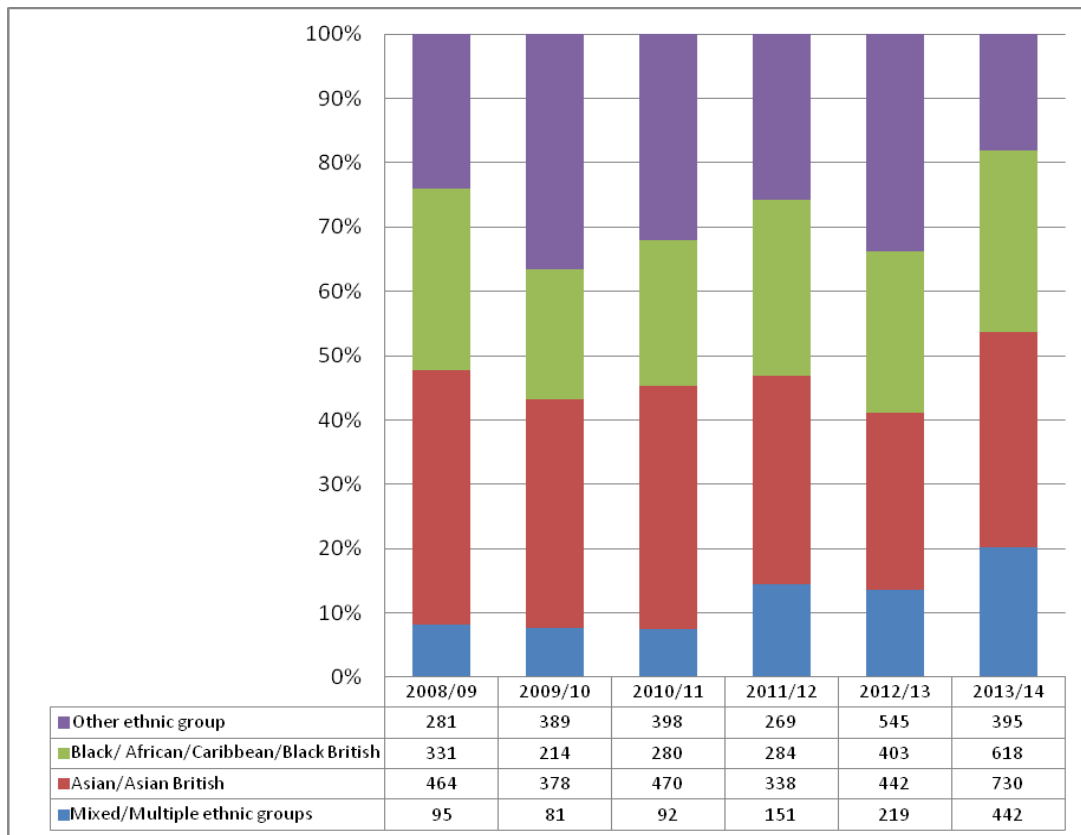


Figure 6.11: people accessing Outpatient clinics from grouped BAME categories, 2008-2014 (Table 94)